The Experiences, Needs, and Internet Use of Women Recently Diagnosed With HIV

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Women constitute an increasing proportion of persons diagnosed with HIV in the United States. From September 2007 through June 2008, in-depth interviews were conducted with 20 women diagnosed with HIV in the previous 12 months to explore their experiences immediately following their diagnoses. Most women had at least a high school education (90%) and were African American (45%) or Hispanic (15%). Analysis of transcripts showed that: (a) many women were surprised by the diagnosis because they did not fit the profile of people at high risk for HIV, (b) obtaining social support immediately after an HIV diagnosis was a primary need, and (c) HIV had an impact on a woman's role in her family. We concluded that strategies are urgently needed to identify women at risk for HIV in a timely manner, and addressing the unique experiences and needs of women recently diagnosed with HIV is critical to their well-being.

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The Centers for Disease Control and Prevention (CDC) estimate that more than 56,000 new HIV infections occurred in the United States in 2006 (CDC, 2010). From 2005 to 2008, approximately 26% of new HIV cases in the 37 states with confidential name-based reporting were among women (CDC, 2010). Eighty percent of new HIV infections in U.S. women have been attributed to high-risk heterosexual contact (i.e., heterosexual contact with a person known to have HIV or at risk for becoming infected with HIV; Prejean, Song, An, & Hall, 2009), and from 2005 to 2008, there was an estimated 9% increased incidence of heterosexually acquired HIV in women (CDC, 2010).

The wide availability of antiretroviral therapy (ART) has resulted in a general decrease of both AIDS-related deaths and AIDS diagnoses in the general population, shifting what was, with few exceptions, a terminal disease to a chronic medical condition. However, only small reductions in AIDS diagnoses and AIDS-related deaths have been made among some groups in the United States, including African American women, women living in the

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South, and persons who were infected through heterosexual contact (Karon, Fleming, Steketee, & De Cock, 2001). A review of the current epidemiology of HIV in the United States noted that Black and Hispanic women accounted for 82% of HIV infections, although they only constitute 24% of all U.S. women (Vermund et al., 2010). These trends suggest a continued need to understand the experiences of, and resources used by, HIV-infected women.

Prior research has suggested that women's experiences in managing their HIV diagnoses may be different than men's experiences (Health & Rodway, 1999), and that women often experience higher levels of stress and poorer health-related quality of life than their male counterparts (Gordillo et al., 2009). Although HIV-related mental health problems are common among persons of all genders, isolation and depressive symptoms are reported to a greater extent among women (Health & Rodway, 1999; Gordillo et al., 2009). High levels of depression have been reported in up to 60% of HIV-infected women, which in part may be related to the stressful demands of women's roles in family life (i.e., caring for children) that continue after their diagnoses (Levine, 2002). Diagnoses of other diseases, such as cervical cancer, have been shown to impair women's body images by fostering feelings of shame about a disease that is perceived to be associated with promiscuity (Ashing-Giwa et al., 2004). Women who are ethnic minorities may experience additional burdens of stress, as those diagnosed with HIV also typically have low-incomes (CDC, 2010) and often lack the family support that is important to optimize health outcomes (Ashing-Giwa et al., 2004). Some researchers have suggested that these and other stressors may lead to inadequate self-care and more rapid disease progression in HIV-infected women (Vanable, Carey, Blair, & Littlewood, 2006).

Poor mental health outcomes among HIV-infected women may be mitigated by a number of factors, including HIV information–seeking and social support. The availability of health information online has dramatically affected how adults access health information and other resources to manage chronic diseases (Fox, 2007). The Internet may be an important resource for persons recently diagnosed with HIV (PRDH; Courtenay-Quirk et al., 2010; Horvath et al., 2010). Previous studies have shown that the use of the Internet and/or HIV-related chat rooms as a source for health information is associated with more effective coping strategies, higher CD4+ T cell counts, and lower HIV viral loads among people living with HIV compared to those who do not use the Internet (Kalichman et al., 2005). Social support has both direct and indirect health benefits for HIV-infected women. For example, a study by Siegel and Schrimshaw (2000) revealed that HIV-infected individuals with strong social support were more likely to experience slower disease progression and improved overall health compared to those with weaker social support. Another study showed that social support, particularly for African American women, increased self-care and adherence to ART (Edwards, 2006).

Although the Internet may provide an efficient way for PRDH to seek and find HIV information and social support, a recent study of HIV-related Web pages found that an online search using common HIV-related search terms yielded only four Web pages that specifically addressed the needs of women (Horvath et al., 2010). The lack of online information specifically targeting HIV-infected women is concerning, and little is known about how these women use the Internet to manage their HIV diagnoses. In response to these gaps in the literature, we conducted in-depth interviews with women recently diagnosed with HIV to: (a) explore their perceptions of their HIV diagnoses, (b) understand which needs were most salient following their diagnoses and the degree to which online resources were available to meet those needs, and (c) examine whether women expressed unique concerns and demands related to their gender roles and new health status. This study is unique because it captures the experiences of women who were diagnosed within the previous year, which may be a critical period of physical, mental, and emotional adjustment for many HIV-infected persons (Kremer, Ironson, & Kaplan, 2009).

Methods

Overview

This study was part of a larger project to explore online resources used by PRDH (Courtenay-Quirk et al., 2010). Based on the current epidemiology of